

Direct payments and the social model of disability

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Abstract: *Despite learning about the social model of disability in social work training, it is difficult to see how new workers can apply this model in practice in a care management system that seems so service- rather than needs-led. Against this background, the advent of direct payments is a major opportunity to promote choice, control and independent living at the heart of twenty-first century social care. While direct payments can seem like a challenge to the role and professional expertise of qualified social workers, they are a unique chance to deliver genuine empowerment and person-centred, needs-led approaches in a system that all too often does not let its workers strive to achieve these goals.*

Key words: *Social model of disability, direct payments, Independent living*

Introduction

When I wrote my personal statement on my application form for a place to train as a social worker, I said that I wanted to go into this profession to 'help people'. At the time, I had done a lot of voluntary work, and was keen to enter a similar field where I could use my skills to develop a rapport with people and 'help them' through periods of difficulty. If I am honest, I had no idea what I meant by this, or what sort of professional role this implies. Is a social worker an 'expert' who assesses people and gives them what the worker thinks they need? A 'navigator' who understands the statutory system and helps people find their way around it to get what they think they need? A 'gatekeeper' protecting public resources? An 'agent of the state' controlling behaviour and enforcing various social standards and norms? An 'advocate' for the person in need? Perhaps even a 'public servant', using their skills and access to resources on behalf of the citizens they are there to serve?

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Ironically I still do not know what I think a social worker is, and the recent Green Paper on the future of adult social care, *Independence, Well-being and Choice*, asks very similar questions about the future contribution of social work (Department of Health, 2005, pp.35-36):

In order to put people at the centre [of services], many will need help and support to clarify their views on the support they want and to access the services they need... A number of models have been suggested and we would like to explore the range of options further, to identify the most promising and cost-effective means of providing support. [This might include] a person-centred planning facilitator..., a care manager..., a care navigator..., a care broker.

However, when I was accepted onto the course (in spite of my naivety) and read about a social model of disability, it literally transformed my life. For the first time, here was a completely different world view that helped me to re-examine concepts I had always taken for granted and to practise in a very different way. In short, the idea that disability, mental illness, old age and other social divisions can be social constructions rather than biological realities was a very simple and yet very radical learning experience for me, with profound implications for my subsequent work and career.

Despite the development of a social model of disability from the pioneering definitions of the Union of the Physically Impaired Against Segregation and the Disabled People's International (see, for example, Oliver and Sapey, 1999 for a summary), the medical or 'personal tragedy' model remains dominant in many areas of society. In medicine, social security, the media and probably the wider public perception, disability is an individual issue that resides within the person concerned, rather than a social phenomenon shaped by environmental and attitudinal barriers to participation and inclusion. Even in social work – with a longstanding history of trying to view the individual in a wider social context and of challenging wider social and economic inequalities - disability remains a predominantly individual and medical issue. While social work students may write essays about a social model, they are qualified in order to work in social services departments which employ professionally trained 'care managers' to assess disabled people and determine their eligibility for a relatively prescribed set of services against a series of increasingly narrow and restrictive criteria. Of course, I would argue that good social work can do much more than this, but this often feels as if it is in spite of current policies and procedures not because of them. Crucially, this comes from an explicit and formal mandate to act as a gatekeeper to scarce public resources, but also from an informal tendency for human services workers to become 'street-level bureaucrats' (Lipsky, 1980; Davis *et al.*, 1997), using informal methods to limit the demands made upon them and make their workload more manageable. This can include making assumptions about their service users, categorising them and making stereotypical

responses to their needs, thereby adding a degree of stability and predictability to their work. In the current context, examples of this might include using screening mechanisms, computer-based assessments and eligibility criteria to restrict access to their time and resources (Davis *et al.*, 1997; Ellis, *et al.*, 1999).

Hardly surprisingly, this situation leads to low staff morale as well as to considerable dissatisfaction and unmet need from service users. While user concerns about the limitations of social care services are described in more detail below, the evidence suggests that social care staff are facing increasing demands, that services are struggling to recruit and retain staff, and that many workers are thinking of leaving due to factors such as low morale, stress, poor pay and working conditions (see, for example, Balloch, 2005).

Against this background, the passage of the 1996 Community Care (Direct Payments) Act is a potential landmark in the history of social work and offers a unique opportunity to promote a more social model of disability. Described as holding out 'the potential for the most fundamental reorganisation of welfare for half a century' (Oliver and Sapey, 1999, p.175), the Act enabled social services departments to make cash payments to adult service users in lieu of directly provided services. These payments could then be used to employ personal assistants of the disabled person's choosing or to help meet their assessed needs in ways which the individual felt was most appropriate. Subsequently extended to other user groups (for example, older people, the parents of disabled children, carers and 16 and 17-year old disabled people), direct payments are now mandatory rather than discretionary and there is government expectation that direct payments will become a major feature of social care (Department of Health, 2005). At first glance, such optimism and official commitment seems difficult to explain: in 2003, there were only 12,585 people receiving direct payments compared to some 1.68 million using community care services (Department of Health, 2005, p. 33). However, to understand the importance of direct payments, it is necessary to understand the history of this policy, the benefits direct payments can bring and the challenges they provide for current social work practice.

The history and advantages of direct payments

Initially, the campaign for direct payments was led by groups of disabled people keen to exercise greater choice and control over their services and over their lives. Having pioneered the concept of direct payments and indirect payments (paid by local authorities via a third party such as a voluntary agency to avoid legal prohibitions on making cash payments to adult service users), disabled people's organisations were responsible for lobbying parliament, commissioning independent research, developing support services for direct payment recipients and sitting on the advisory group which produced official guidance on payments (see Evans, 2003; Glasby and Littlechild, 2002 for a summary).

Figure 1 Choice and control

For many applicants, the ILF was not just about making up for unavailable statutory services. It was the preferred option. From a disabled person's point of view, the provision of cash makes the important difference between having one's personal life controlled by others and exercising choices and control for oneself. Money has enabled ILF clients not only to avoid going into residential care, but also to determine for themselves the help they require and how and when they want it to be provided. In many cases, where that freedom and corresponding self-respect are not central components, care in the community may be no better than institutional care. (Kestenbaum, 1993b, p.35)

Thus, from the beginning, direct payments were a policy developed and owned by the disabled people's movement. More than any other current policy, direct payments were pioneered and piloted by disabled people, campaigned for by disabled people, and implemented and made to work by disabled people. This alone marks direct payments from other ways of working, but just as significant are the fundamental challenges that this poses for social work and the opportunities it offers to reconnect with why many people came into the job in the first place.

It is now widely accepted that direct payments enhance choice, control and independence. In the early 1990s, research into the Independent Living Fund (ILF) (a predecessor to direct payments which provided funds to enable certain groups of disabled people to employ their own care assistants) revealed that making cash payments directly to service users gave a sense of control and choice that could not be achieved via statutory services (see figure 1; Kestenbaum, 1993a; Lakey, 1994). While respondents found directly provided services to be inflexible, costly and severely limited in terms of the availability and level of service on offer, they valued the freedom which ILF payments provided. Receiving money with which to employ their own personal assistants (PAs) enabled them to choose staff with whom they felt at ease and who they felt had the right strengths and skills. The disabled person could also employ someone of a particular sex and select carers who spoke the same language as they did. Above all, however, ILF recipients valued being able to hire staff with whom they felt able to develop a good relationship, choosing people with the right personality to make the care package work. As a result of this, the disabled people were able to establish and maintain longer lasting relationships with their staff and enjoyed greater continuity of personnel. At the same time, they were also able to create flexible support arrangements to meet often fluctuating needs. Throughout a number of research studies, respondents repeatedly emphasised the control that ILF payments gave them and the self-respect that they felt as a result of their status as an employer. Rather than being dependent on others to determine and meet their care needs, the disabled people themselves could determine what Kestenbaum (1993a, p.38) describes as 'the what, how, who and when of care arrangements.'

Also in 1993, respondents in Jenny Morris' study of disabled people's experiences of community care services emphasised the many advantages which employing PAs could bring (Morris, 1993, pp.125-126):

I'm a husband, a father and a breadwinner. And ten years ago I was in an institution where I couldn't even decide when I would go to the toilet.

It means that I can get up in the morning when I want to, and lead the kind of life that I want to... To not be reliant on my family and friends... to keep all that separate [so that] to them I'm me rather than someone who needs help.

It means exercising choice and control, having the right to choose who gets me up and who puts me to bed.

I'm living on my own, living in the way I like. I can come and go as I like.

I employ people..., which allows me to have the life style that I choose. (disabled people employing PAs)

In 1994, similar findings emerged from Zarb and Nadash's study for the British Council of Disabled People (BCODP). For many respondents in this study, indirect/direct payments were crucial in enabling recipients to control the times support was provided, who was employed, what sort of assistance was provided and how it was provided, thereby enhancing quality of life and personal dignity. Overall, the most important aspect of a payments scheme was found to be having choice and control over one's own support arrangements, which in turn led to more reliable and flexible services that enabled needs to be more fully met (Zarb and Nadash, 1994, p.90 - emphasis in the original):

I am in control. I can decide when I want help. The way help is delivered – I feel it is *my* life, not someone else's. You are not fitted in to other people's time table. Freedom – you can choose *who* you have. If you don't like them you can have someone else. You can choose the manner in which a task is performed, unlike when home care staff are used. It releases me to have family as family and friends as friends. (direct payment recipient)

After the implementation of the Community Care (Direct Payments) Act in April 1997, further research has emphasised the centrality of choice and control for direct payment recipients. For Peter Brawley, then chair of Glasgow's Centre for Independent Living, direct payments have been a major step forward for disabled people (quoted in Hunter, 1999, p.10):

For people such as myself, for whom the traditional option would have been institutionalised care, being able to choose a personal assistant has made a great difference. I am living with my wife in the community, going out to work every day. It gives us the chance to maximise our potential and take our proper place in a changed world.

In 1999, a study carried out by the Social Services Inspectorate found that direct payments recipients were more satisfied with their care arrangements than people receiving direct services, citing feelings of control as a key factor (Fruin, 2000, pp.15-16). For one service user in particular, a direct payments scheme had 'just turned everything around - it has given me self-respect' (quoted in Fruin, 2000, p.16). In Norfolk, all respondents in an evaluation of a local direct payments project saw the scheme as a means of gaining more choice and control in their daily lives, empowering them to live their lives as they chose (Dawson, 2000, p.17). This was also the case in Scotland, where recipients valued the opportunity to exercise choice and control, contrasting this with previous disempowering experiences of direct services (Witcher *et al.*, 2000, para.6.10):

Things couldn't be better now. It's given me much more freedom and control and I play a more active role in family life. Choice, freedom and control sums it up for me. It has been amazing, my life has completely changed. (direct payment recipient)

The importance of choice and control have also emerged as key issues from publications produced by organisations of disabled people such as the National Centre for Independent Living (NCIL). In 1999, NCIL guidance for local authorities began by stressing that direct payments are a means to an end and a way of achieving independent living (Hasler *et al.*, 1999, p.5):

Of all the advice given by disabled people who use payment schemes, people who run support schemes for payment users and those who commission payments schemes, one starting point emerges clearly and firmly: it's about independent living. Every aspect of a direct payment system needs to be geared to enabling disabled people to achieve maximum choice and control in their everyday lives.

A similar message also emerges from NCIL's *Rough Guide to Managing Personal Assistants*, which highlights many of the difficulties of employing PAs, but ultimately re-iterates the centrality of the increased choice and control that direct payments can bring (Vasey, 2000, pp.129-130):

Disabled people are forever being cast as vulnerable, hence the services that support us tend to be overprotective. Direct Payments are about the right to take risks, to learn, like everyone else does, from our mistakes and to develop into wiser, stronger people.

That is independent living.

Having PAs enabled me to find out who I am and now enables me to be who I am.

Of course, enjoying greater choice and control depends on the way in which direct payments are operationalised by individual local authorities and on the support services available: being paid an inadequate rate that does not allow you to meet your own needs and being left to make your own arrangements without support is hardly liberating or empowering. In many areas of the UK, the level and type of support available varies considerably, and there is clear evidence to suggest that the presence of a user-led Centre for Independent Living is a crucial element in many successful schemes, offering people access to much valued peer support (see Glasby and Littlechild, 2002, pp.120-123 for a summary). With a growth in user charges and tightening eligibility criteria, moreover, some direct payments recipients may find it difficult to meet their needs effectively, and there is also clear evidence that some social services departments fail to recognise hidden costs such as recruitment, training, National Insurance, sick and maternity pay, insurance, contingency funding and enhanced rates for specialist skills or anti-social hours (see for example, Hasler, 1999; Leece, 2000; Morris, 1993; Witcher *et al.*, 2000; see Hasler *et al.*, 1999 for further details of recommended on-costs to include in direct payment calculations). As Vasey (2000, p.10) argues:

Some of the difficulties [of direct payments]... could be sorted out by a more substantial Direct Payment. Without enough money independent living becomes stressful and in some circumstances almost too stressful... Money is one of the key factors in the crusade. It is both liberator and jailer and we have to resist all attempts to minimise care packages and maximise charging. If we fail then we will be in big trouble. We will have no money to pay for the other parts of our lives (mortgages, children, vehicles) or to pay for the other mammoth costs associated with significant impairment.

In addition to this, there are other problems associated with receiving a direct payment: recruiting staff, a lack of information and awareness about current services, and the difficulty of overcoming previous poor experiences and disempowering services (see Glasby and Littlechild, 2002; Hasler 2003 for a summary). However, these are all issues to do with the way in which direct payments have been operationalised and implemented, not a product of the concept of direct payments, which remains an extremely simple and powerful way of working (see Glasby and Littlechild, 2005 for further discussion).

Challenges to social work?

At first glance, the advent of direct payments seems to be a challenge to the role and professional expertise of qualified social workers. With access to cash payments with which to employ their own staff, the disabled person becomes the manager of their own care, deciding what services will best meet their needs and securing these within the resources available to them. Recent policy documents have also placed significant emphasis on self-assessment, as in the current social security system (see, for example, Department of Health, 2005), and this too touches on territory that some workers have traditionally regarded as their own. Contrasted to the heavily regulated nature of directly provided services, direct payments can seem inherently risky, exposing so-called 'vulnerable people' to the danger of being exploited by unscrupulous staff and left with their needs unmet if their care package breaks down. Although this is a recurring theme in much of the direct payments literature, two examples are quoted below from a Social Services Inspectorate review of independent living (Fruin, 2000, p.17):

I am very worried about direct payments – vulnerable people managing their own services. (Social worker in a multi-disciplinary team)

Can I risk [direct payments]... on behalf of clients? (Adults team social worker)

For some workers, moreover, direct payments are a form of 'privatisation by the back door' (Hasler *et al.*, 1999, p.7) and a threat to collective, public sector services (Glasby and Littlechild, 2002; Pearson, 2000). That direct payments were initially introduced by a Conservative government committed to neo-liberal politics and to 'rolling back the frontiers' of the welfare state has not helped to quell these concerns. Also significant is the post-war history of adult social care – due to a desire to distance modern social work from the stigma of the former Poor Law, adult social services have historically been separate from social security and have not been involved in making of cash payments to people in need. As a result, the advent of direct payments (although very different from social security payments to people in financial need) could be argued to run counter to nearly half a century of social work practice and requires significant cultural change (Glasby and Littlechild, 2002).

For these reasons, direct payments have been resisted by some front-line workers as a threat to traditional ways of working (see, for example, Dawson, 2000; Fruin, 2000; Glasby and Littlechild, 2002; Hasler *et al.*, 1999). That this is sometimes the case is deeply to be regretted, as direct payments offer the opportunity to revolutionise social care and to promote choice, citizenship and independent living – the very values and principles that social work has traditionally espoused. This state of affairs is perhaps best summarised by Bewley (2000, pp.14-15) in relation to direct payments and people with learning difficulties in a long but important quote:

My involvement in the promotion of direct payments does raise questions for me about the current state of play in care management. Care managers are extremely important gatekeepers in the whole direct payments story. I have a strong impression that people... who have been able to access direct payments have always had a champion on their side. This has often been a forward-thinking (and tenacious) family member, independent advisor, advocate or, sometimes, care manager. These care managers have been vital in the promotion of direct payments so far but they are not the majority within social services. If direct payments are to become an easy mainstream option... then enabling people to access them must become normal care management practice. For this to happen, significant change is required to individual, team and organisational practice around care management... The care management system is under many pressures and the truth is that direct payments are not a daily priority for many care managers... This is a shame because the ethos of direct payments is extremely exciting. Care managers now have the chance to actually give service users the money to buy their own services. This sharing of power, this chance to see individual lives flourish whilst practical support needs are met, is a fantastic opportunity for care managers to be inspired by their job. The opportunity is there.

Conclusion

Although modern social work can sometimes feel as if it is characterised by low morale, by protecting access to scarce resources and by 'street-level bureaucracy', the advent of direct payments is an opportunity to deliver genuine empowerment and person-centred, needs-led services. While some social workers may view this as a threat to traditional ways of working and to their personal power and authority, others will welcome direct payments as a liberating policy that allows them to work *with* rather than *for* service users and to promote a more social model of disability. By giving disabled people direct access to resources with which to employ and manage their own staff, direct payments help to promote choice and control over people's services and hence over their own lives. As such, it is one way of achieving greater independent living and of beginning to tackle some of the social barriers to greater inclusion and participation. Despite tremendous potential, however, the choice is up to individual social workers as to whether they take this opportunity to promote access to direct payments or whether they withhold information, make assumptions about users' ability to manage payments and block progress. If I were applying for a place on a social work course now, I would still express my aspiration to 'help people', but I would see direct payments as a crucial weapon in my armoury as I qualified and began to practise.

Acknowledgement

This paper draws and builds on an earlier introduction to direct payments: Glasby and Littlechild's (2002) *Social Work and Direct Payments*. (Bristol, Policy Press).

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